

*“There is no grave marked HIV, and there is no grave more
than six feet deep”*

**Exploring the meanings of death and dying and
the burden of living with HIV/AIDS
in Soweto, a South African township**

Natalya Dinat

A research report submitted to the Faculty of Health Sciences, University of Cape Town
Department of Public Health, in part fulfillment of the requirements for the degree of
MPhil in Palliative Medicine

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Declaration

I, Natalya Dinat hereby declare that this report is my own unaided work. It is being submitted for the Degree of MPhil in Palliative Medicine at the University of Cape Town (UCT), South Africa. It has not been submitted or presented for any degree or examination at this or any other university.

Supervisor Dr Elizabeth Gwyther, UCT

Ethical Approval from UCT- reference 260/2003

_____ day of _____ 2005

Dedication

To my husband Jimmy, my son Cian and my parents for all their support, patience and understanding.

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I would like to acknowledge the following people for their contribution to this study:

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“Man is not destroyed by suffering, but by suffering without meaning.”

Victor Frankel. A survivor of the Nazi concentration camps.

INTRODUCTION

To die from AIDS in developing countries is, more often than not to die with extensive pain and suffering (1). Internationally and nationally it has been accepted that this pain and suffering can and should be alleviated, (2) and whilst there have been some efforts to provide palliative care for people with AIDS in South Africa, there is a dearth of evidence-based care, and scant documentation of evaluation of programmes, policies or the services which attempt to render this type of care.

South Africa subscribes to the international principals that treatment, care and support for people infected with HIV/AIDS should include a “full package of services” or be provided along a “continuum of care”. These should include psychosocial support, counseling, medication for opportunistic infections, antiretroviral therapy and palliative care(3) Whilst the alleviation of the pain and suffering accompanying AIDS has been made the responsibility of the relatively young discipline of palliative care, together with social development agencies (governmental and international agencies) and the “community” in the form of NGOs and CBOs, the 2004 Report on the Global AIDS Epidemic (UNAIDS, 2004) has found that one of the most neglected aspects of HIV care is palliative care.

Research into appropriate and effective delivery of palliative care and pain and symptom relief has 'fallen off' the international research agenda as witnessed by only 1.7% of accepted abstracts at the July 2004 International AIDS Society Conference in Bangkok. South Africa, with one of the highest HIV prevalence in the world, is experiencing a highly visible and rapidly increasing number of people very sick and dying of AIDS(4). Between 1997 and 2003 there has been a 57% increase in reported deaths in South Africa (5;6) which has been largely attributed to HIV/AIDS(7) and in 2004 almost 500,000 people die of an AIDS related illness that is more than 600 people each day(8).

This research was undertaken as an exploratory work prior to setting up a novel palliative care model in Soweto in 2002. It was undertaken to identify areas which need to be addressed in more detail; to identify needs of people with AIDS, the context in which this has arisen and to find out whether the response has been largely appropriate.

From the late 1980's reports emerged of palliative care services and home-based care services being avoided or not welcomed by service users and their families(9) (Hospice Africa Uganda, Wits Hospice in Soweto, South Coast Hospice - personal communications). Perceptions were that using the service stigmatized them, or that an admission to hospice would confer an immediate death sentence. This research wanted to hear from services users themselves and their families about their experiences, their concerns, their needs for a palliative care service for people infected with AIDS to inform the setting up of an appropriate, more acceptable and therefore effective service.

Part of this research, which was conducted at the end of 2002 – 2003 forms the basis of this thesis. Namely, the perceptions, meanings, experiences and main concerns of services users and service providers who are dealing with advanced AIDS and deaths from AIDS.

HIV/AIDS has been recognized as a multi-faceted disease requiring a multidisciplinary or interdisciplinary research. However, most research has been conducted from either classical anthropological discipline, or biomedical, or sociological disciplines, with little or no collaboration. Studies are scant in the area of palliative care, HIV/AIDS and dying, this may be in part, because care of the dying is a grey area that is not clearly biomedical or social. Whilst care of those with both acute and chronic illnesses have been medicalised and has been seen as clearly within the biomedical domain, the management of a death remains firmly in the social and cultural domain.(10)

This thesis is divided into three main sections; the first section is a literature review, in turn divided into three subsections; which considers a conceptual framework for stigma as pertains to terms of acceptability of a service; health care needs and appropriateness of services; looks at arguments when prioritizing cultural versus structural versus psychological considerations in service delivery; finally outlines current theoretical approaches to death and dying, and explores some areas of incongruence or slippage between current theories and palliative care approaches recommended in the major textbooks.

The next part of the literature review will describe the context of contemporary life in Soweto in a “time of AIDS”. It will provide a brief historical context to death and dying in

Soweto and highlights the major events which have impacted on the socio-political landscape as it affects home-based care and palliative care.

This third part of the literature review will describe the mortality data from South Africa, and compare with mortality data from other middle-income countries, countries with high numbers of AIDS deaths, and countries where palliative care models emanate from.

The second section will describe the aims of the study, the methodology used on this study, the rationale for using a qualitative methodology, credibility, conformability and transferability of the data; the sampling strategy, data collection, data analysis, and ethical considerations.

The final section will lay out the findings of the study, discuss these findings in the light of current literature and make some recommendations for palliative care services in a high HIV prevalence setting.

LITERATURE REVIEW

There have been few studies published on the clinical needs, welfare needs and psychological needs of people dying of AIDS or cancers, the needs of their families after death, and the meaning death has to people in developing countries. Studies on the needs of the dying in Kenya (11) and Uganda (12) and South Africa (13) have shown that drugs for pain relief, food and physical needs were important. A study comparing needs and uses of services in Scotland and Kenya found that patients from Kenya thought that their psychological, social and spiritual needs were met by their families, local community and religious groups. The authors concluded that the lived experience of illness was different in the two settings, as well as there being a difference in availability of resources (14).

Stigma has been cited as a major barrier preventing seeking a range of AIDS-related medical care. Hospices throughout Africa have reported that people are unwilling to use their services, either inpatient or home visits. NGO's providing home-based care have reported difficulties in enrolling patients (personal communication and Soweto Care Givers Forum report). At the same time the complexity of this phenomenon is evidenced by the fact that treatment availability has been argued to decrease stigma. Parker and Aggleton argue that issues of stigma, discrimination and denial are poorly understood, and that there are relatively limited theoretical and methodological tools available to us (15). They argue for a move beyond the behavioral and psychological models that have tended to dominate work, to understanding the social processes that reproduces social difference; and the cultural, the political and economic determinants and consequences of stigmatization.

UNAIDS has reported that “Stigma and discrimination associated with HIV and AIDS are the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating impact.”(16) They define stigmatization as a process which devalues, which significantly discredits an individual in the eyes of others. It has important consequences for the way in which individuals come to see themselves.

UNAIDS have cited many forces which contribute to triggering stigma and discrimination. They include “lack of understanding of the disease, myths about how HIV is transmitted, prejudice, lack of treatment, irresponsible media reporting on the epidemic, the fact that AIDS is incurable, social fears about sexuality, fears relating to illness and death”

Stigma often results in marginalization from services, and social isolation, loss of self-worth.

Stigma in the West has been explained primarily because HIV is a sexually transmitted illness, first noted as an epidemic in the gay community

Theoretical frameworks on death and dying and its implications in caring for the dying and bereavement care.

Despite the belief that death is a taboo subject, works, both scientific and popular, abound on the subject. Neil Small notes that systematic research on death and dying appeared in the aftermath of the Second World War. (17)

Research on illness, dying and death in developing countries has mainly centred around anthropological accounts of death customs, and rituals in ‘primitive societies’ and the traditional beliefs associated with sickness, death and dying, with few exceptions, notably that of Marcus.(18) This contrasts with research in illness, death and dying in Western

Countries which have largely taken a psychological or biomedical approach or has been rooted in sociological disciplines.

In Western countries, psychological approaches to grieving and bereavement and the dying process were developed. In a review by Middleton (19) theoretical models of bereavement were ranked according to importance. The two highest ranking were psychological approaches, with roots in Freudian and Jungian theory; a sociological model ranked third, followed by other psychological models and lastly a model based in ethology (biological and physiological processes underpinning bereavement phenomena across species). Thus, emphasizing the dominance of stage theories of attachment and psychodynamic process in the west over the past 30 years. These reactions describe grief. The theories are based on seminal works by Kubler-Ross, Parkes, Bowlby and Worden. There are distinctions amongst each theory, but most include a phase of shock, a time of disorganization and a process of reorganization. These emotional responses have also been seen as a “normal” response, so leading to definitions of “abnormal” or pathological grief(20).

Recent work in the literature has questioned the validity of this approach, recognizing the complexity, the dynamism and interrelatedness of issues. There has been a call for a consideration of psychological, structural and ethnological factors when studying dying and death and when proposing interventions.(21) For Example recent theories proposed by Stroebe describe a process of continuing bonds and accommodating the new realities. The emphasis here is on coping via a dynamic process oscillating between loss-oriented and restoration-oriented.

Sociological models for grief and bereavement can also be applied to understand loss. Small welcomes recent works, which locate their approaches in prevailing social theory. He suggests that we can move towards a theoretical position that recognizes diversity and is not framed by a wish to categorize or control. He postulates that “the process of loss and change occur in a variety of social and cultural contexts, which are mediated by historical and other perspectives”. These change according to historical and other perspectives. For instance how we grieve after a war, a natural disaster, loss of an elderly member of the community, loss of someone with high social status, loss of a child

Current palliative approaches are generally based on attachment theories, and encourage accommodation of an individual’s cultural beliefs when applying these theories to practical care. Gunaratnum writes critically of the ‘fact file approach and ‘culturalist’ approaches recommended by palliative care guidelines in the UK(22). She questions a report from the National Council for Hospice and Specialist Palliative Care Services (Hill and Penso 1995), which identified a need for the provision of ‘culturally sensitive’ services... in relation to Black and ethnic minority service users. Needs of Black and ethnic minorities in the UK, she argues should not be assessed only in terms of their culture and religion, but also by understanding the sociopolitical context and the dynamics.

Similarly in HIV/AIDS studies, cultural values, beliefs and practices are often seen as static and unaffected by the disease impact itself; associated with ethnic origin (African American, Hispanic, Asian, Africa) or religious belief(23). Parker has also pointed out in a paper on HIV and AIDS related stigma that in the west, stigma is generally conceived as an individual process – or as what some individuals do to other individuals; this makes little sense in other environments, where social and cultural phenomena are linked to the actions of whole groups of people(24).

Social and cultural aspects of illness and death in South Africa

Colonialism and Apartheid had profound effects in shaping the ways South Africans view illness and death. African culture in South Africa (including language, values, history, religion, literature, the arts, African medical knowledge) was largely suppressed during colonial times and in the apartheid era to the extent that much of this knowledge is now lost, or been denied to the masses of people. It was substituted by widespread adoption or assimilation of British traditions, the Christian religion, and post 1945 a noticeable and growing American influence, especially as regards popular culture.

In the 1950's -1960's communities were fragmented by the often violent and forced removal of populations and the migrant labour system. From the 1970's to the end of the 1980's some geographical areas were severely affected by the exodus of large numbers of young people being forced into exile. All these factors and the deaths of political freedom fighters are likely to have helped shape the unique and specific meanings assigned to death in contemporary South Africa and particularly Soweto.

Recently the magnitude of AIDS related deaths in South Africa has been an issue of controversy. As the South African Government, in particular the Presidency has been engaging in AIDS denialist debates (25) it has questioned various reports on AIDS mortality calculations and been silent when the huge numbers of deaths have been talked about. On the other hand media reports of cemeteries filling up, endless funerals, teachers dying, nurses dying, deaths of colleagues, and families experiencing multiple deaths affect daily lives of the majority of South Africans. So much so that as Dowling has described in her paper ‘

Naming and talking about HIV/AIDS in African Languages' HIV has been named thus; 'The Killer of the Nation - Umbulalasizwe (Xhosa); Mmolai wa Setjhaba (Sotho) or The Finisher of the Nation - UQedisizwe (Zulu) .

She goes on to say that 'HIV/Aids has become a famous African personality, feared and hated, but to some extent wondered at for its power and ability to wreak havoc on a nation."

Soweto- background

Soweto was the chosen site for this study, since the model of palliative care was to be piloted here. Soweto is the largest township in South Africa. It has a population of about 1, 2 million. It is located 25kms to the south west of Johannesburg, but part of the Joburg Megacity jurisprudence. Although in Gauteng, the industrial "powerhouse" of South Africa, Soweto is described as peri-urban or urban. It has high unemployment levels, and a variety of socio-economic levels from extreme poverty to middle income. The wealth of Joburg masks huge inequalities in wealth, access to education and health care services. Soweto's population is fairly stable, and is of mixed ethnic origins (mainly either isiZulu speaking or Sesotho speaking). Since the forced removals of people started in the late 1950's to Soweto, there has been a fair degree of marrying and social interaction. As a result Soweto has been described as a 'melting pot', with its own unique identity (26) There are about thirty active home-based care organisations operating in this area. The services provided vary tremendously in quality and it is difficult to estimate the actual coverage in Soweto (personal communication)

Soweto is well-known as the epicenter of the political uprisings by students in 1976 which sparked violent reactions from the state. It has been home to two Nobel Prize winners (on

one street), and has a history of highly organized political activism, that extended into all aspects of community life. The Regina Mundi Catholic Church was a hub of political activity when there were extensive bannings, censorship and state violence. At this time funerals of young people killed by the state were commonplace. Since it was the only opportunity for people to gather together legally, it was not uncommon for funerals to become occasions for mass mobilization.

After the political violence ended 10 years ago and against a slowly decreasing background of violent crime Soweto is now witnessing increasing numbers of AIDS related deaths.

Currently there are more than 150 funerals each week in Soweto (personal communication, Alan Buff, Joburg City Parks and Cemeteries). There is a high HIV prevalence, currently 12.9% in the general population (27)

Sowetans live in proximity to private healthcare, primary and tertiary/quaternary level care. In Soweto there are 23 public primary health care clinics, a large teaching hospital, which functions as a level one, two three and four hospital, another tertiary level hospital (nearby in Johannesburg), a number of general practitioners (private), two private hospitals, and traditional healers and pharmacists. Standards of care vary tremendously and there are no formal widely used standard referral criteria between the different providers and levels of care. Treatment and care for AIDS has been haphazard and patchy.

It is worth noting that the Chris Hani Baragwanath Hospital is also accessed by patients from the Province, the country and even the region.

Mortality patterns in South Africa

South Africa has a unique 'epidemiology' of death when compared to most other developing countries in Africa or other middle income countries. Even in the 'pre-AIDS' era, and in living memory, death rates amongst young people in South Africa have been high as a result of poverty, state violence, crime, unintentional and intentional injuries.

Measurements of death rates for most countries have shown a consistent and familiar pattern; a peak in death rates in the first few weeks of life, which falls and remains steady, then starts rising again in late middle age to old age. Developing countries differ from developed countries in that they often have the same patterns with a larger death rate at birth and in young children and lower average life expectancy. Proximal causes of death in developing countries are mainly attributed to infectious diseases and injuries, both intentional and unintentional. (28;29)

In South Africa there is, in addition another significant peak in early adulthood. Some of this has been contributed to by a notoriously violent colonial and recent history. An estimated 20 000 people died as a consequence of political violence between 1984 and 1994 (Goldstone 1998).

Death from unintentional injury, homicide, motor vehicle accidents in South Africa were the highest in the world. A recent newspaper article compared road fatalities per 100 – million vehicle kilometers travelled in South Africa. In 2003 fatalities were 10.4 per 100 million vehicle kilometers traveled. (Source: South African Department of Transport). The United States Department of Transport currently gives the US fatalities per 100 million kilometers as 0.91 – this makes it more than 11 times safer to driver in the US than in South Africa. (Mail and Guardian Newspaper 25th Feb– 3rd March 2005)

The additional impact of AIDS has been quantified by the Burden of Disease (BoD) Report of the South African Medical Research Council which states that 'Analyses of more recent data, including the sample data for 1997-2001 reported by Statistics South Africa, highlight an improvement in death registration and also show how SA has moved from a triple burden of disease to a quadruple burden, comprising poverty-related conditions; emerging chronic diseases; injuries and AIDS.'

The report goes on to quantify these deaths, in South Africa, 'HIV/AIDS is now the leading cause, accounting for 30% of all deaths, followed by cardiovascular disease (17%), infectious and parasitic excluding HIV (10%), malignant neoplasm (7%), and intentional (7%) and unintentional injuries (5%). Perinatal conditions, respiratory disease (chronic), respiratory infections and diabetes make up the balance of the 10 leading sub-categories.' In 2005 55.8% of deaths will be due to AIDS.

This effect of AIDS on the age specific death rates has not gone unnoticed by South Africans. From an ethnographic work by Wood in Umtata, the Eastern Cape a pastor, speaking at funeral noted:

In these times, he said, everything is changing. Before, it was scarce to find young men dying, but now the youth are getting sick. Before, if you had a newborn baby and it was small, you would be afraid for it, afraid that anything might happen, but once it crawled and walked, nobody would worry because that infant would grow up and live to old age. Now the youth were dying, and elders often buried their children.(30)

This extremely high death rate amongst adults in South Africa has affected the population pyramid, and AIDS will distort it even further. There has been a decline in the numbers of elderly people, and a relative increase in the numbers of youth.

HIV/AIDS and home based care

The South African Government's policy (National Strategic AIDS Plan for 2000 – 2005) has stated that the pain and suffering experienced by those with AIDS be in the main addressed by a home and community-based care approach. Integrated Home and Community Based Care (IHC) is one of the top five priorities in the National Strategic AIDS plan. The IHC model mainly involves shifting care of the dying from hospitals to peoples' homes, and from health professionals to family and community members. Home-based care is also intended to include care of those with terminal illnesses other than AIDS.(31)

Home based care was further endorsed in November 2003 when the cabinet ratified the Comprehensive AIDS care plan, which set out HIV/AIDS care and treatment guidelines for the public health sector along a whole spectrum of care including free antiretroviral treatment.

Palliative care and AIDS

Palliative care concerns itself with how to care for dying people and their families. The World Health Organisation defines it thus: “ Palliative care is an approach that improves the quality of life if patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment if pain and owht problems, physical, psychosocial and spiritual” (2002). It has been under development in the west for over 30 years. Prior to the pioneering work of Cecily Saunders and her coworkers, care of the dying and those with incurable illnesses were largely carried by religious organisations or by the household. As the demand for a response from the medical fraternity became more vocal, the philosophy and medical discipline were born. In the West palliative care is still largely provided by the Hospice Movement, but can also be found in some state health care settings. In developing countries palliative care is still nascent and almost wholly funded by donor organizations. Models of care differ and palliative care is provided in community (home), hospital and institutions.

There is a general consensus that palliative care services like other medical services needs to be evidence based (32;33). The dearth of methodological tools, clinical trials, best practice models has led to difficulty in setting standards and assessing the acceptability and effectiveness of services. Terminology and understandings of concepts remain vague or open to multiple interpretations. Including, even the understanding of what home and community based care is, or “treatment, care and support” of those with AIDS is. Studies conducted on home based care services in South Africa, have therefore come across a range of methodological difficulties but have concluded that shown that the range in quality of care provision is large. (34)

Understanding meanings of death and illness and health seeking behaviours is important if utilization of health services is to be optimized. Underutilization of home-based care services and hospices in high need settings have been reported in other African countries and in South Africa and have been attributed to stigmatization of these services.

AIMS AND STUDY OBJECTIVES

This research is part of a larger study, of which Dr N Dinat is the principal investigator. The aspect reported here is on the health seeking behaviours of people with AIDS, and their expectations of care. The main study purpose was to inform a proposed model of palliative care in Soweto, the N'doro model, to identify an acceptable approach for a palliative care service in Soweto, and find out which issues were of concern to the people who would be potentially receiving these services.

The aim is to understand meaning of death and dying and the burden of living with HIV/AIDS.

Objectives are:

- 1) To understand the beliefs and lived experiences of Soweto residents as regards living with HIV and dying of AIDS; their experiences in seeking health care;
- 2) To document their needs in terms of palliative care for HIV/AIDS, including needs for bereavement care and how these are interconnected.
- 3) To feed the results of 1) and 2) back to NGO's and public health institutions involved in care, and to assist in improving health and welfare policies.

RESEARCH METHODS

Rationale for use of qualitative methods

This is an exploratory work and a qualitative research methodology was deemed to most appropriate. The chosen methodological framework comes from the disciplinary tradition of

social anthropology, which lies within a naturalist paradigm. Because the goal of this study was to inform a model of palliative care from the service users' perspectives and the service providers' perspectives, we needed to understand social phenomena on natural (rather than experimental) settings, giving due emphasis to the experiences and views of all the participants. House-visits were conducted where possible with permission to witness for ourselves the living conditions otherwise interviews were conducted where interviewee felt most comfortable. Permission was obtained to visit the care centres to observe care practices. This work would prepare the ground for other qualitative and larger quantitative studies.

Credibility, conformability and transferability

Rigour and credibility of the research was assured where possible through the process of triangulation, whereby information is only used when confirmed by two other sources.

These included an examination of the relevant literature on the burden of disease and mortality data, use of focus groups, observation and fieldworkers' notes and examination of patient notes. The fieldworkers were selected for their prolonged engagement with Soweto, they had all lived or grown up in Soweto, and had previous experiences in conducting interviews in Soweto.

Conformability refers to the extent to which the results presented conform to the data collected. This is ensured by the use of quotes, which have been translated from local languages or used verbatim in colloquial English.

Transferability of the findings of the experiences of Sowetans to urban or peri-urban South Africa can be expected. The majority of South Africans live in urban settings and due to the Apartheid system and rapid urbanization strong links with the rural areas are common.

South Africa has 11 official languages and Soweto has been described as a melting pot of many South African cultures. In addition, being the largest township in South Africa and , housing the largest hospital a diverse population of South Africans visit Soweto for health care.

The researchers

The field workers (NS, ZR, and BM) are anthropologists and have grown up or currently live in Soweto. The principal investigator is a medical doctor has lived in a community of exiles, mainly Sowetans, for over 10 years, and then worked in Soweto for over 11 years.

The main fieldworker (Nokuthula Skhosana), an anthropologist, is well versed in researching sensitive subjects in this area (completed and accepted masters thesis in “women, HIV and stigma, life in a hospice in Soweto”, from the Department of Anthropology at the University of the Witwatersrand).

Sampling

A purposive sampling frame was designed to identify people with stage IV HIV infection, their informal carers or family, professional carers (nurses), home based carers (lay carers with 59 day training), traditional healers, leaders of faith based organisations and families who had been bereaved. The sampling frame was applied to ensure diversity with respect to age, gender, family size, employment, household income, service contact and treatment access.

Data collection

Altogether 59 one-to-one in-depth interviews were conducted, seven focus groups (2 with male persons living with HIV/AIDS (PLHAs), 1 with female PLHAs, 1 with lay caregivers, 2 with trained caregivers, 1 with traditional healers).

Data was obtained during 57 one-to-one interviews using a structured guide with open-ended as well as semi-structured questions, focus group discussions using a structured guide and via participant observation.

Written informed consents as well as interviews were conducted in Zulu, Xhosa or Sotho or English or a mixture of the languages, as requested by the participant. They were tape recorded then transcribed and translated into English by field workers. The field workers have been trained in research methods, live or have grown up in Soweto, and so have an understanding of local colloquialism. There were discussions around the translations (general accuracy, as well as clarifications, innuendos and meanings) between the investigators and translators. A scope of enquiry was used to guide the interviews and focus groups. The interviews took place in a private environment, and field notes were written immediately afterwards. The focus groups were led by a trained facilitator.

Table 1. Broad Scope of enquiry

Demographic information
Making sense of AIDS – how do you think of AIDS?
Living with HIV.
How has AIDS in the family, community impacted on life in general?
The challenges that are posed by AIDS in the home
Sources of support: the nature and extent
HIV/AIDS and emotions Fears and worries

Living with an anticipation of death and dealing with death
Needs and if they are met
Nature of training and its adequacy for challenges met
Thinking about and dealing with dying
Thinking about the body at death
Needs at this stage of life and if they are met, and experiences with the health care system

Data Analysis

Data was analysed using systematic thematic analysis. Although data analysis rarely proceeds in a step-wise manner, the following processes were used to provide a framework for analysis.

Familiarisation with the data through immersion in the transcripts formed the initial stages of the data analysis. Transcripts were read and reread in order to become familiar with the content.

Identifying a thematic framework. The main issues, concepts and themes emerging from the text were identified. During this phase the researcher reread the transcripts making notes and drawing diagrams which formed an initial grouping of similar topics, and these groupings were refined as data analysis progressed.

Key phrases in the text were highlighted using different coloured highlighters and cut out and pasted onto sheets of paper, thus clustering the issues with similar content. The phrases were coded to identify which interviews they had been taken from.

Categories

The sheets were used to identify categories as groups of issues and to formulate themes in order to answer the research question. This allowed flexible organisation of data supporting the developing themes. Common properties in the initial categories pointed toward links in categories that supported grouping these categories into the emerging themes and sub-themes.

Themes

Data that appeared to relate to different sub-themes were further compared and analysed to identify the most relevant to each theme. The initial induction of themes following the analysis of focus group data was refined by constant comparison with the themes emerging from the individual interviews, and the fieldworkers' observations. The process of constant comparison resulted in exploring themes more fully and revising the analysis until the structure described the results in a coherent and valid form.

Endpoints were reached when the interviews did not yield new categories of data and saturation of themes were reached.

Ethical considerations

Ethical approval was obtained from the University of the Witwatersrand Ethics Committee (protocol number H020802) and from the University of Cape Town (reference number 260/2003). The committees considered both medical and social science aspects. The proposal included a written informed consent form, participant information sheets and referral mechanisms to support services if or when required.

Informed written consents were obtained for each of the interviews, and individual written consent were used obtained for the focus groups. They were available in English, isiZulu, seSotho and siXhosa.

For getting access and recruiting informants: Families of HIV infected people were only interviewed where granted written permission by ill person concerned. HIV infected people were first approached by nurses trained in GCP, and asked if they would want to participate in the interview. Thus their HIV status was not exposed to the fieldworker without the patient's permission.

Families of HIV infected people were only interviewed where granted written permission by ill person concerned. HIV infected people were first approached by nurses trained in GCP, and asked if they would want to participate in the interview. Thus their HIV status was not exposed to the fieldworker without the patient's permission.

The research assistants were trained in how to approach potential participants and obtain informed consent, the appropriate interviewing techniques, study protocol as well as ethical conduct by Nokuthula Skhosana and Natalya Dinat as well as the PHRU counsellor-psychologist, Robin Hamilton. The research assistants were closely supervised during the entirety of the fieldwork, by way of twice weekly meetings with Skhosana, biweekly with Dinat and weekly with the counsellor-psychologist. The first focus groups and individual interviews were conducted by the researchers were attended by N Skhosana to ensure sensitive and correct interviewing. Feedback was provided and researchers will be allowed to interview alone once the supervisor was satisfied. All fieldworkers were offered debriefing after the interview sessions.

Confidentiality was maintained in the following manner: Participants were advised not to use real names, and were referred to in the results using a code. Individual interviews were conducted in private areas, out of earshot of others.

We sought written consent of ill people to interview their families, and the interviewers were instructed not to reveal any information given by the ill person, which included medical diagnosis, history and prognosis. Interviewers were trained particularly on how to handle questions from concerned family members, in order to maintain confidentiality. They were asked to sign a clause to protect the confidentiality of the informants. Researchers did not conduct interviews or focus groups with people that they knew.

Risks to participants

The researchers acknowledge that the interviews may have resulted in some people requiring referral for counselling, psychological support, information on HIV or have medical needs that pertain to the area of research. If this occurred the participants was referred to the appropriate centres for assistance. In the event that a participant became very upset during the interview they were offered a support session, by an experienced psychologist-counsellor. The three researchers will be trained on how to deal with this and other serious situations requiring emergency action, before the study.

FINDINGS

Interviews took place between September 2002 and January 2003.

The findings of the interviews are presented in the following sections;

- Profile of informants
- The main experiences and concerns of people dying with AIDS and their carers' experiences and concerns. These were concerning issues of;
 - denial and stigma
 - losses and becoming a burden
 - interactions with the health care systems (formal and informal);
- The needs of people living with HIV/AIDS;
- How Sowetans deal with dying and death

Fieldworkers' observations and comments

Summary of profile of informants.

Interviews of People living with HIV/AIDS (PLHAs)

All PLHAs had been pre and post test counseled, had a documented HIV result, and the majority had had an AIDS defining illness, for which they had sought treatment. Some had been ill for a few years. In total 22 people with HIV/AIDS were interviewed, 17 were women. Informants were recruited from hospice (6), hospital (2), and NGO support groups (14). Most of the women were single mothers and unemployed. The youngest was 17 and the oldest was 42 years old. A number of them had lost their jobs because of recurring illness and were financially dependent of their family. Only 7 were receiving a disability grant, with two exceptions these were from Hospice Soweto. Disability grants are allowed

for people with either a documented CD4 count of below 200 per mm³ or an AIDS defining illness and were R600 per month at the time of the study. Some were taking antiretroviral therapy as part of clinical or programmatic research. Quotes from PLHA are designated P1-P22.

Service providers:

There were 32 interviews from service providers. Five were professional nurses, trained in palliative care, working either at the Chris Hani Baragwanath Hospital (State hospital) or the Soweto Hospice (non-profit privately funded). There were 4 social workers, each from a different institution, four traditional healers (working as private practitioners), two pastors, 12 community care givers (working in the NGO sector). The community carers were lay people who had received a short (59 day) training course in home based care. Six project managers were also interviewed. They managed the home based care projects, and provided direct care to the patients.

Family carers

Five family members were interviewed; four were mothers of the patients and one a grandmother. Three had buried their children from AIDS.

Focus groups

There were seven focus groups; 2 with male PLHAs (FGM1, FGM2), 1 with female PLHAs (FGF) 1 with lay caregivers (FGL), 2 with trained caregivers (FGP), 1 with traditional healers (FGT).

The interviews are tabulated below

Table 2. Demographic information of informants - PLHA

PLHA	Age	gender	Employment status	Grant recipient	Marital status	Number of dependents	Family circumstances
P1	32	f	n/e	yes	single	3	was cohabiting but now stays with sister in family house
P2	35	f	n/e	yes	single	3	
P3	35	f	n/e	no	divorced	2	Stays with mother
P4	36	m	n/e	yes	Married	3	wife and children
P5	33	f	half employed	no	married	3	extended family
P6	24	f	self-employed	no	single	2	mother and siblings
P 7	17	f	n/e	no	single	1	extended family
P 8	18	f	n/e	no	single	1	extended family
P 9	31	m	Employed part-time	no	single	0	cohabiting
P 10	34	m	n/e	no	single	n/a	was cohabiting now with extended family
P 11	25	f	n/e	no	single	0	grandmother
P 12	29	f	n/e	yes	single	2	nuclear family
P 13	32	m	Employed	no	married	1	nuclear family
P 14	40s	f	n/e	no	single	0	cohabiting
P 15	32	m	n/e –was working	no	single	0	extended family
P 16	28	f	employed as counselor	no	single	1	cohabiting

P 17	30	f	n/e	no	boyfriend	2	extended family
P 18	42	f	n/e	In process	single	1	extended family
P 19	28	f	n/e	no	single	1	extended family
P 20	32	f	n/e	no	single	3	extended family
P21	23	f	n/e	no	single	0	extended family
P 22	28	f	n/e	In process	single	2	cohabiting

Table 3. Demographics of service providers

Service provider	Gender	Service	Affiliation	Qualifications	Status of employment
Sp 1	f	Counselor/hbc	CARE/Mofolo	Std 10/ 52 days hbc course	Full time
Sp 2	f	Counselor/co-director	SOHACA	Tertiary/trained counselor	Full time
Sp 3	m	counselor	Mother's s/g (PHRU)	Tertiary/counseling	Full time
Sp 4	f	coordinator	DAPP	Std 10	Full time
Sp 5	f	hbc manager	DAPP	Prof. nurse	Full time
Sp 6	f	caregiver	ACCT		Full time
Sp 7	f	caregiver	Soweto caregivers	Std/52 days hbc course	Full time
Sp 8	f	Counselor/hbc	HWW	52 days hbc course	Full time
Sp 9	f	Counselor/hbc	HWW	52 days hbc course	Full time
Sp 10	f	Counselor/hbc	HWW	52 days hbc course	Full time
Sp 11	f	Counselor/hbc	HWW	52 days hbc course	Full time
Sp 12	m	counselor	Selby Park	Prof. Nurse/lifeline	Full time
Sp 13	f	Social worker	Soweto hospice	Social work	Full time
Sp 14	f	Social worker	Selby park	Social work	Full time
Sp 15	f	Social worker	Carl Sithole	Social work	Full time
Sp 16	f	Social worker	HWW	Social work	Full time
Sp 17	f	Prof nurse	Soweto hospice	+palliative care	Full time
Sp 18	f	Prof nurse	Soweto	+palliative	Full time

			hospice	care	
Sp 19	m	Traditional healing	independent	Traditional healing	Full time
Sp 20	m	Traditional/spiritual healing	independent	Traditional healing	Full time
Sp 21	f	Traditional healer	independent	Traditional healing	Full time
Sp 22	f	counselor	Itereleng-Itsoseng project	Assistant nurse	volunteer
Sp 23	m	Project coordinator	Emthonjeni	tertiary	Part-time
Sp 24	f	Prof nurse	Bara hospital	+palliative care	consultant
Sp 25	f	Prof nurse	Bara hospital	+palliative care	Full time
Sp 26	f	Traditional healer	Zifozoneke traditional healers	Traditional healing	Full time
Sp 27	m	pastor	Izikhova ezimqini	tertiary	Full time
Sp 28	m	pastor	Holy Apostolic Church in Zion	secondary	Part time
Sp 29	m	coordinator	Kliptown Youth project	Std 10	Full time
Sp 30	m	Counselor/youth educator	MS CARE	Std 10 / counseling	Part-time
Sp 31	m	counselor	MS CARE	Std 10/counseling	Part-time
Sp 32	m	Coordinator of project	Itsoseng project	?	Part-time

Table 4: Demographics of lay caregivers

Lay caregiver	Gender of caregiver	Relationship	Status of patient	Gender of patient
Lcg 1	F	mother	deceased	m
Lcg 2	F	grandmother	Still alive	m
Lcg 3	F	mother	deceased	m
Lcg 4	F	mother	deceased	f
Lcg 5	F	mother	Still alive	f

Findings of the interviews, focus group discussions and fieldworker observations are presented below. As in any situation of extreme and desperate circumstances, occasions of deep love, caring, hope and growth were witnessed. Positive experiences that have been extracted out of this epidemic on an individual and societal level were also described by some informants, and some are touched on the section on coping. However the overwhelming experience of AIDS was that of great suffering.

Table 5: Themes, categories and subcategories

Themes	categories	Sub-categories
Stigma	Disclosure Causes of HIV, why me? Denial	Pollution of illness and death Multiple beliefs existing in parallel
Lived experiences of HIV	Money Food Pain and symptoms	Burden of poverty Dependence Fatigue and distress Maintaining hope and hopelessness
Experiences of health care system	Health care workers Hospital	Reasons for going and not going Needs
Experiences of home-based care	Distress and benefits	
Experiences of other care systems	hospice	dependence
Traditional healing	Trad healers & users opinions	Effective treatments, stigma, pollution
The Church	roles	Religion , sin, laziness, promiscuity, love, strength from prayer
Rituals and death	Hard to get information	Pollution, changes, discrimination

Sowetans' experiences of being ill with AIDS

The AIDS epidemic has become very visible in the past few years. In general, informants had all had personal experience of AIDS amongst their families, neighbors and friends. The multiple exposures to loved ones suffering then dying had not numbed the pain over time.

A nurse explained

(SP24): Let me tell you something, in my family, in one week on a Tuesday, Thursday and Saturday, and the youngest was 19 years they died of aids all of them in a week, and she has left 3 children. The youngest is two months and it's very sad. The family couldn't attend the funerals because it's every day and we have to go to Evaton and Mofolo really it's very sad.

A lay carer spoke of the effects of witnessing multiple deaths

(FG4) You know sometimes it becomes very difficult. There is counselling that we need because we get to be very close with these people. Others live for two years and you go to them everyday. You know that they (patient) are going to leave you. And at the end they leave you. You remain very disturbed – you are not all right.

A grandmother told of how she cared for her third son, relating her story was difficult and tiring and she had a headache after the interview.

(LCG2) My two sons have committed suicide before and I was in a very difficult situation and I had to leave my house and live with him (third son) because I was afraid that that he would commit suicide.

In interviews and focus groups informants wanted to talk more about living with HIV, stigma and other problems faced and were reluctant to talk about death and dying.

It was recognized that AIDS was accompanied by significant and multiple pain and symptoms. Health care workers often related that death was welcomed as a relief from the pain and suffering. When asked about the main causes of suffering, fatigue was identified as a very distressing symptom. Stigma and resultant isolation (social death) was discussed in terms of dependence on others, becoming a burden to others. The roots of stigma was seen lying in the fact that AIDS was an incurable illness (not in the fact that it was sexually transmitted), and issues of it being a polluting illness was discussed.

Denial of major symptoms

Soweto cultures have been largely derived from Zulu and Sotho cultures with influences from some other language groups and areas. Zulu customs expect stoic behaviour during illness, without expression of pain and suffering. Ngubane (1977) in her ethnography of the Nyuwasa-Zulu states that “malinger is treated with great contempt”, and “as soon as a person can get up, he is expected to do so, for it is believed that lying down, unless absolutely necessary weakens the body, whereas getting up and moving about helps towards recovery”.

These beliefs and values were evident in this study. Fatigue was a commonly reported AIDS related symptom and its presence caused a large amount of distress. The patients felt that although they were exhausted after doing daily activities, it was not a recognized condition or symptom of their illness, and thus likely to be interpreted as laziness or sloth. This was compounded by the fact that weakness and fatigue was not a progressively worsening condition, but could get better or worse on a daily basis. For the carers, fatigue was sometimes interpreted as ‘put on’ or an excuse to hide laziness. It also caused distress

because the fatigue could be quite debilitating and lead to a dependence on others. One PLHA said;

(P20) *"But I am ok now as long as I can walk and be able to do things for myself. The only problem is that I get tired all the time. Sometimes you do things because there is no one that will do it for you but your body is painful. And when you talk like that people think that maybe you are lazy"*

Losses experienced by people with HIV/AIDS – social deaths, ‘otherness’ and stigma

A social death happens long before the physical death. Causes of social deaths in this study were linked the loss of being able to contribute to family, community or society coupled with increasing dependence on others. It was often accompanied by a loss of self-identity and self-worth. *"now a person is a scrap"*. This was a source of great pain for one informant, who felt this loss of independence, when as an adult she was forced to be subservient to her mother, with whom she did not generally get on with. The informant also reminded health workers that home based care may be inappropriate, for not everyone has their own home, or not every one wants to be in their own home.

(P4) *"how can you provide home-based care when people have no homes?"*

(P4): *"I am in a mess, my mother is bully naturally and I have to be submissive because I am staying in her house, and I am eating her food and I must live according to her standards and that one is worse"*.

Financial dependence led to people staying in relationships or with family that they may not have ordinarily stayed with. In some circumstances the financial dependence was seen as the main reason for tensions in the home.

(P5) *“I stay with my partner... The only reason I am staying with him is to get food because I cannot work anymore”*

(P2) a former teacher : *“my greatest need which I can say it is priority is the accommodation as I did previously indicate that staying with parents is not working. We have differences.”*

Dependence on others, even trained community care workers from home based care groups caused humiliation and misery.

P15 [on how home based carers can help] *bathing you..., I would try even if it was difficult but I tried so that she wouldn't find me dirty”.*

Both patients and carers believed that most of the tasks performed by home-based carers were the responsibility of the (extended) family/neighbours, so home-based care provided by ‘outsiders’ was often seen as a last and desperate measure for the most destitute. This brought an extra dimension of humiliation to the patient.

Becoming a Burden

Becoming a burden to family was a source of suffering and has resulted in loneliness and isolation for many. Soweto houses migrant workers, who go “home” once or twice a year, but there are also many second, third and fourth generation Sowetans have a ‘rural home’. Urban dwellers are often expected to support the rural home with money and goods. When

this became impossible some informants preferred not to impose on them and so have “lost” their rural homes and roots, another potential or only source of comfort and care.

P3 “To go back home it is not good especially if you are going to be a burden. so you visit when you know that you have money and you will buy food. Unlike just taking the bus and say I am going home without money, you are going to put those people at home in trouble. So to live this life is difficult you just wait until God take you. I don’t want to make people struggle.”

The burden extends after death since it is customary for people to be buried in their ancestral home. The cost of transporting bodies long distances has become prohibitive for many. This perpetuates a downward spiral of being denied proper rituals, which denies assigning meaning to death. Burials outside the family homes are significant in that it disturbs the ancestors and is often attributed to be the cause of a cycle of bad luck for the clan or extended family. The improper funeral rites for one member of a family can thus adversely affect a whole family, such are individuals connected to one another and their ancestors. Often families were faced with the difficult decisions of paying for a proper burial or paying for the care of the living.

(FG1) “he was from Kwa-Zulu Natal but was staying in a hostel and his family came to fetch her. Imagine the expense of transporting the body from here to there because the wife and the kid have nothing and are staying in this one room in the hostel.”

Another common reason cited for stigma associated with the disease was the fact that AIDS is incurable and fatal.

(SP20) *“why people stigmatise people with this disease... People were sort of terrified by what they were told about the disease itself, that there is no cure, once one contracts it the end result is death. So that terrified the people”.*

(SP19): *they hide it because people were told that this thing does not have a cure so they don't want to talk they prefer to suffer alone”*

(SP26) *“Some they give up on life and do risky things... What will make a huge difference is when people hear that this thing is curable, because people will have hope that they will live again. But because there is no cure everyone is hiding it”*

Stigmatization of AIDS has been explained by the fact that it has all the criteria for a high degree of pollution (a notion common in many Bantu cultures). It causes an untimely or premature death, from an incurable illness, it causes disfigurement of the body (wasting) and a darkening of skin colour, ‘their faces turn pitch black’ (photosensitivity).

Informants in this study cited pollution as superstition that ‘others’ held, which needed to be combated with ‘education’.

In modern day Soweto, the notions of pollution and the western idea of infectiousness and infection control measures are often extended to cause discrimination amongst the living.

Wasting and physical changes accompanying this disease is a source of great distress to people with AIDS and their families. A nurse explained this;

(SP23): *What I think cause discrimination is that when an HIV person is infected and is at the terminal stage or is bed ridden she/ he changes a lot and facially or physically. So the family would not even want to come nearer such person because he is so scary and they are afraid that they will be infected.*

The hyper pigmentation of the skin due to photosensitivity is common in AIDS. This 'blackening' or darkening of the face has also been interpreted as a sign of dirtiness, pollution, or devilish behaviour.

Beliefs held that corpses and the bereaved emanate a form of pollution, which may be contagious. Handling the corpse also causes pollution. The cause of death also affects the degrees of pollution. An untimely death from an incurable disease (including epilepsy or TB), death from accidents, fighting or murder are particularly polluted. Since pollution is contagious, merely by being near someone or the corpse is further reasons for isolating behaviour. It was common that the corpses of people who died in accidents were not brought into the home. However, when asked if burials of people with AIDS were different these days most informants said no. A nurse went out of her way to reassure patients that there would be no issues of pollution in AIDS

(SP 24): *And I would say we are all Gods people and we are all going to die, it doesn't matter how we are going die we will die in different ways, it can be a car accident, gun shot, aids, cancer, TB it's the same because we are going to die. Then my patients feel better and become stronger.*

Whilst it seemed that different funerals were not common in Soweto, notions of pollution were still be extended to the living as a cause for isolation.

(P5) *“in most cases when people know that you have it, they don’t even greet you, they just think that once they open their mouths you will infect them.”*

Experiences of the Health care system

In the apartheid years and indeed in the 10 years of democracy the health care system has principally emphasized curative medicine. Although there has been a shifting emphasis toward primary health care, treatment of chronic diseases and palliative care has received a low priority. Although people did try to access the health care system at multiple points and repeatedly, they clearly understood that the western hospitals offered primarily a curative service. The notion of palliative care was little known outside the hospice and hospital palliative care team.

(P1) *"In hospitals when they see you are terminal, they discharge you."*

(Sp25) (nurse) *"Doctors tend to attend to people who recover more than people who are suffering from AIDS, cancers etc."*

Nevertheless, informants expected humane treatment from the health care providers whatever the prognosis. A traditional healer voiced a common view, that sickness starts in the mind and by dismissing patients, and saying 'there is nothing more I can do for you' was at best improper and at worst cruel.

(SP19) *"statements like those kill"*

Informants perceived a recent deterioration in the quality of care, and worsening attitudes of the health care workers towards them.

P 6 *"everything has changed... the nurses are so rude these days. These days no-one wants to go to hospital, it is dirty, even the food is bad"*.

P17 *"they do not have the patience, they are tired with our illnesses"*

P 11 *“at xxx clinic, there are no doctors, only nurses... They can see you are really sick, but they will never take you first, you will wait in the queue... they are shouting at you. Can you go back there? No”*

“these days it is very painful to find Bara is full. You find that they do not attend me and end up sleeping in a chair”

“At Bara, I’ll go when I am about to die... but I will go because I have no other alternative”

P1: I have slept [at Bara] twice. At Bara I was discharged before time because my drips always came out and they said I did that deliberately. You know when you are sick some things you cannot control. There was this nurse that was abusing me ...there wasn’t even a doctor but I was discharged

Bad treatment and neglect made the hospital is the last resort from the patients’ perspective. Health care workers often wondered why the patients come so late, too late for them to help.

Experiences of home-based care

“It is a case of the poor looking after the destitute” Consultant to government

Home based care services are provided by non-profit community organizations, often receiving funding from the Government. It is seen as an important part of the Government policy of “treatment, care and support”. Services are provided by lay volunteers. The volunteers are mostly unemployed and are expected to work a 40 hour week for a stipend. The service they provide varies tremendously, although many services will clean the patient, clean their house and cook food. At the time of writing there were no written criteria for accepting a patient onto a home based care programme.

PLHAs, and HBC service providers interviewed in this study has differing expectations of the role and importance of the home based care programmes.

HBC organizations saw themselves as necessary because they were taking some of the strain off the hospitals.

SP30 "Home based care is important because hospitals are ever full there are no beds and etc."

Interestingly, whilst it was expected that drugs were required for the well being of patients, home visits by doctors and nurses were not mentioned. In other words HBC was not seen as a way of taking the hospital to the home, by either care providers or service users.

Expectations of what home based care should provide were ambivalent. PLHAs wanted to be treated at home, because *"in most places they do not have care for people"* but did not want to be washed by the home carers, only by the family. Home based care organisations provided a wide variety of services. Some were very basic, and generally unwanted by the community. Some *"because of a shortage of kits and gloves"* provided *"comfort"* and *"encouragement to go the clinic"*. These did not see patients who were bedridden or were unable or unwilling to go the local clinic.

(SP7) "If they do not go to the clinic, whereas they have cards ... we cancel them, we no longer visit them".

Other HBC groups performed tasks such as washing and feeding the patient, cleaning the house, and *"bed-making as they do in the hospitals"*, and provision of emotional support. There have been comments from them on the fact they often have to *"pop out my money to buy them brown (the cheapest) bread"* This has over time become a national concern of the HBC groups, and tied in with their status as volunteers.

Home-based care groups saw their role as important, but under-resourced. There were complaints that HBC is inadequately funded.

(SP2) 'I think Home-based care is a disadvantage because..., funding is number one, ... if ever there are 10 people sick there should be ten people to look after each of them in every home'

'I can't say it's quality care because we don't have some things and we have to improvise because people are poor out there and you cannot bring your own things from home to look after these people'

Supplies were also erratic.

Importantly they saw their primary role as providing assistance in the home, psychological support. They felt frustrated when they could not address the poverty and hunger or pain and symptoms. This is a great source of stress for them and 'caring for the carer', carers retreat and burnout were commonly voiced areas of concern. They did not see themselves as part of the health care system. In some cases they saw themselves as advocates for the family, others as surrogate family. The exclusion from the health care system and the under-funding caused stress when they saw the need for a patient to be referred to the hospital or the clinic. They would sometimes advise the patient and family, sometimes try to arrange transport, and sometimes keep quiet. Even within the health care system PHC doctors and nurses voiced distress when their referrals to the Bara casualty were turned away.

For these reasons many home-based care organisations in Soweto cannot access patient's homes. Organisations which can provide an in-patient care, day centres, home visits with qualified nurses and drugs are generally more welcome.

One such organisation is The Mofolo Hospice. The hospice in Mofolo is run by the Hospice Association of South Africa.

Traditional healers

Different cultural beliefs and practices are not mutually exclusive. As with different value systems, they can and do coexist in individuals, even when they seem fundamentally contradictory. A traditional healer explained;

SP26; "We see it in two ways, one as a sickness, as a virus, which is dirty, and two, biblically we take it as something that is testing people's faith..."

Many people feel comfortable seeking both traditional and western medicine. They will attend church, a hospital support group, and seek help from a sangoma. The parallel existence of differing belief systems was often difficult for health care workers to accept. They often saw themselves in competition, with other medical systems, and express frustration when patients seek help from dual systems. The traditional healers were also frustrated when they advised patients to seek help at the hospital, but the hospitals did not reciprocate. An important consideration when seeking health care was cost.

Needs of people with HIV

The main needs were; acceptance by others as people who were worthy of care; drugs (pain and symptom relief, as well as ARV therapy), financial support and food. This was not expressed in any particular order or priority, not were the needs mutually exclusive, they were all equally important. It is also worth noting that the state was looked to provide all of the needs (including acceptance or love from the health care workers).

(P9): I want them to love me and not struggle for medication and you see the grant we get it is nothing you just used it cover there and there, there is no source of income.

The extent and type of the suffering and experiences of care from families, public sector and NGO sector have been noted above. The needs voiced were basic and limited. However when considering that the overall expectations of the health service is low, expectations that were basic were no longer a surprise. There were no calls for 'swish' hospices, state-of the art pain relief (syringe drivers), CT-scans.

Food

The need for access to good quality food was mentioned in almost every interview. Concerns about people going hungry and orphans not having any food in the home were a source of distress for care providers, who would provide money for food out of their own pockets. The thought of the hungry would haunt many of them. PLHAs also stated the need for quality food. There was a common belief that eating healthily would delay the onset of AIDS or death, and conversely lack of access to food perceived to be quality led to illness.

(P3) "When you go to the hospice we thought we were going to get healthy food but what we get now are the potatoes. ... but they must give us healthy food with salads and even fruits"

(SP5) "It's food. That is the problem. Also treatment, because they need it as well when they tend to complain about pains.."

There were widespread perceptions that if people ate the “correct food”, they would not become sick with AIDS. What patients discovered however is, that the institutions where expert care for AIDS was provided, food was not seen to be that important or life-saving. The anxiety around accessing ‘healthy food’ was synonymous with food from expensive shops.

(FGM2): When you want fresh vegetables you must go to Woolworth's or grow them yourself because I don't believe that spinach, onions etc could be R2.00, so I think there is something wrong from the food that we eat so how can we be able to fight HIV if we don't eat healthy food. I believe there is something fishy with our fruits and vegetables because you get them on the street for R2.00 where do they get them? You go to Woolworths three Apples are R5.00, why? They should try to make everything we eat or consume to be of good quality

Inability to access a certain quality of food was often cited as reasons for either not getting or not taking anti-TB medication or other medication, such as antiretroviral drugs.

Love and acceptance

Acceptance by the health care system and from individual health care workers was important. Informants with HIV/AIDS felt discriminated against and that they received a second class treatment from the public health care system.

At Bara I was discharged before time because my drips always came out and they said I did that deliberately. You know when you are sick some things you cannot control. There was this nurse that was abusing me

There was a sense of frustration from doctors and nurses, who were unable to provide treatment, therefore were often relieved to discharge the patient from their care to the palliative hospital consulting service.

Many people with AIDS were not afraid of death and some saw it as a welcome end to suffering and discrimination. This was also a commonly voiced sentiment amongst those who had nursed a sick person.

(P10); I am also telling myself that even if I die because of HIV there is no grave written HIV, and also there is no grave that is more than six feet"

Love and understanding of the symptomatology of AIDS was also required.

(P1) I need to be loved and people that are around you must have patience and they must try to understand that you cannot do things by yourselves.

Medication

Informants voiced the need for appropriate and effective medication for their pain and symptoms.

(P18)I think I need pills because every time they give me these pills and I don't get better maybe if I can get different pills or injection I would be better I have hope that if I can see the doctor I will be better. ...?

People saw AIDS as a serious disease requiring treatment by the doctors as opposed to self-medicating with over-the-counter drugs. During the time of the study, both the hospital and the clinics experienced frequent and prolonged drug shortages. Drugs which could provide pain and symptom relief were not available, or the doctors or pharmacists were not available. The palliative care nurses also noted that training in pain and symptom relief needed to be provided to the doctors and nurses. Imodium (for diahorrea) was given in for only three days when it was needed for longer periods of time. Patients would often only receive paracetamol and vitamins for pain and symptoms, which was noted to be inadequate. In addition, clinics also could only dispense medication to patients who are mobile, and able to come to the clinic to be examined in order to receive a prescription. Bedridden, terminal patients had difficulty accessing prescriptions for drugs, unless visited at home by a nurse or doctor.

Non-government health care providers (hospice) also reported difficulties in accessing medication for their patients.

Money and poverty alleviation

Carers and PLHAs reported that income from one person support a larger extended family, sometimes both in Soweto and the rural areas. Inability to provide was as source of great suffering to people. Even if the person with AIDS was unemployed they would be expected to assist the household with unpaid work (such as looking after children, grannies, cleaning). Their illness not only resulted in a loss of income, but also incurred extra costs; of transport, drugs, visits to the clinics/private doctors/ traditional healers, blankets, cleaning materials, funerals and so on.

There was much talk of accessing the disability grants. The focus group reported that people wanted to be HIV infected to get a grant, or of cases they had heard of 'selling results', those with AIDS (a CD4 count of 200 or less or and AIDS defining illness were the criteria for receiving a disability grant) reported not wanting to risk losing the grant and so did not want to get better.

Fieldworkers' observations and comments

It was difficult to get them to talk about death, dying and AIDS. This was the overwhelming response from informants. There was a preference to talk about living with HIV, and a reluctance to talk about dying.

Hospices and step down facilities were not as busy as were anticipated, and difficulties were faced in conducting interviews.

Here there weren't as many patients as one would expect and it was usually practically difficult to conduct interviews in private because of lack of space.

Some support groups were unstable. Services provided in both the public and NGO sector were not always running smoothly and to capacity.

It looks like the groups are in the process of consolidating, the caregivers and partners and the men's groups, which we were particularly interested in have erratic and very poor attendance.

Some challenges faced in researching this difficult area are outlined below.

Disappointingly, we have not had patients refer us to 'their' traditional healers although this might, in fact, be an important finding.

Patients are not particularly keen on us getting in touch with their caregivers.

It has proved particularly tricky getting recently bereaved families to be interviewed. Those that we were referred to and approached pleaded that it was still early and they were still emotionally raw and, therefore, could not partake in the research. However, some caregivers that we have spoken to have already lost their children, relatives etc.

How Sowetans cope with dying and death

As stated above, it was difficult to do the interview and get data on what meanings are assigned to death and dying in Soweto. People stated clearly that they do not think about death.

This can be linked to the widespread notion that dwelling on illness or hardship makes one ill or accelerates the dying process. So it becomes a matter of survival not to worry or dwell on death. Many informants questioned why the researchers are doing a study on death and dying, and suggested that it is more important to do a study on living with HIV.

One PHLA, he stated that

(P15): others don't survive long because they think too much

In addition, anxiety about death was not widespread. After the initial shock of learning one's status, many came to terms and accepted the fact that they would die. It was taken as a pre-ordained fate, which will come to each person *'the day when I die.'*

(P14): like now I know death is there... And I have accepted death when time comes but what I want now there are things I want to do in my house, it is not something big but just few things and I'll be ready for my way it is ok.

(P1): I don't have fears I know that all sick people die.

(P5): I just tell myself that God is there I will die when my time comes

As much as there was an acceptance of death, mothers with AIDS did not want to resign themselves to death. They were worried about the future of the children. This was very much a source of distress.

(P2): I wish I could have my own house so I could stay with my children

(P11): now I wish that if God can help me and get well so that I can send my child to school.

Healthcare workers

The enormity of the epidemic, and the suffering associated with it was felt by many workers in this field. Nurses, lay carers and others related the additional burden of not being able to leave AIDS behind at the end of a working day because they were either infected themselves or had family members who were infected, or had died. When asked how they coped with this those who received supervision or debriefing found that it did not help or helped a little bit. Some had found a purpose in helping others.

An experienced social worker, who had received training in palliative care, found that the training was difficult to implement practically.

(Sp13); some things look good when someone is lecturing...the practicality of it is what kills you most...

She noted that, although the training does encourage cultural sensitivity

(SP13) "so whatever training you get they try as much to be culture sensitive but it doesn't make you to be immune to this emotional burden that you suffer from".

This questions the appropriateness of emphasizing 'cultural sensitivity' in care, when, as she explains *"the reality of it is so overwhelming"*.

The strong language she uses demonstrates the extent to which she is also suffering when caring for her patients.

DISCUSSION

The discussion of the findings, their meanings in the light of the literature and their implications for a palliative service are presented as follows;

- Denial of major symptoms as a source of suffering; this looks at fatigue and local expressions of pain and symptoms
- Stigma of poverty, pollution, and fatal illnesses; this examines some other common roots of stigma in Soweto
- Needs of patients and their families and their expectations for palliative care services
- Approaching living with HIV and dying from AIDS through a cultural or a sociological lens
- Limitations of the study

Denial of major symptoms as a source of suffering

Fatigue is one of the most common symptoms of AIDS. In a study of 103 patients in Soweto, with stage 4 AIDS (WHO staging) 42% complained of fatigue, and fatigue ranked number one problem from an study of 1128 patients in Italy. (35;36)

Fatigue in AIDS has been not been recognized as a major debilitating symptom by the health care profession in South Africa , perhaps for the reason that drug treatment of fatigue has not been very effective and expensive. This coupled with the fact that many South African cultures expect stoicism n the face of ill health, especially from women, has caused much distress. Ngubane writes that it is customary that people who are ill may feel the pain, but are expected to go on with his tasks, sick but '*nhamba nako*' (he goes about with it). If a person has to lie down (*ulele pansa*) this suggests that something is serious and those around him become concerned(37). With the convoluted disease progression of AIDS, it becomes unclear as to whether this disease warrants someone to lie down or not. People with AIDS can experience bouts of debilitating illness followed by periods of relative wellness. If this is not understood and acknowledged by health workers, explained to patients and their families it is perceived as 'laziness' (a sin in Christianity and also frowned upon in African culture), which, when added to the promiscuity (another 'sin') is another reason for stigma.

Many health education programmes on AIDS for both lay people and health professionals have failed to address this aspect of the AIDS disease, thus, in effect denying permission for people to feel legitimately exhausted by routine tasks. Lack of knowledge about fatigue presents difficulties when trying to reset goals and realistic expectations of functional status. Kikule's' work in Uganda showed that the dependence and becoming a burden to others was one of the main concerns of the terminally ill(38). This was also noted in Soweto. It placed a strain on relationship dynamics, it sometimes resulting in patients isolating themselves. This

concern is of a much higher priority for patients in developing countries, than in developed countries(39). Recognition, by the health profession and peer educators, of fatigue as a debilitating symptom, emphasizing that it is not the patient's fault, and strategies to address should be important priorities for palliative care.

Stigma of fatal illnesses and poverty using pollution, sin and infectiousness to discriminate

Stigma is a complex phenomenon, which characterizes HIV/AIDS. Goffman (1963) defined stigma as 'an undesirable difference'. Stigma and discrimination was an important concern of the informants. Explanations by informants as to why AIDS was a stigmatizing condition were different to those commonly at the heart of anti-stigma programmes. The UNAIDS has found that much HIV/AIDS related stigma is because HIV is associated with sex; homosexuality, promiscuity (by women), multiple partners, loose sexual morals. Informants in study have cited the main reasons for stigma is not because AIDS is acquired sexually but; the fact that AIDS is incurable and associated with poverty. To play out, justify or enforce this discrimination a "new hybrid" of cultural and religious meanings have evolved and continuing to evolve.

The most common explanation of stigma could explain why many palliative care and hospice programmes had difficulty in accessing patients. Namely the fact that AIDS is incurable and fatal (this research was carried out before the 'roll-out programme" of anti-retroviral drugs). That people will continue to die from AIDS will mean that they will continue to avoid hospice care. A possible way to address this is by an education campaign

which will emphasise the other two no less important roles of hospice: pain and symptom relief and respite care.

Stigma may also be reduced by providing quality medical care and treatment such as excellent palliative care (home visits by professionals, adequate pain relief) and access to antiretroviral therapy. Further evaluation is underway of this palliative care programme in Soweto to look at this. There have been suggestions in the literature that access to treatment reduces stigma. A proxy measure for the reduction of stigma is the willingness to come forward to be tested for HIV, or the uptake of condoms. Documented experiences in Khayelitsha, Masaka in Uganda and Cote D'Ivoire have all demonstrated that care (ARV treatments in these cases) increased condom use and use of VCT services. Interestingly concerns about sexuality, promiscuity and loose morals were seen as old-fashioned and incorrect factors for stigma, amongst many of our informants. A church pastor, interviewed has noted that AIDS can even infect a virgin.

Becoming a burden financially to a family was a major concern. This has also been found in Kikule's and Murray's work. An economic study of over 4000 households in Soweto showed that poorer families with AIDS infected 'fell further' than middle income families with AIDS (40). Having money can 'buy life' as Edwin Cameroon has so written eloquently about on his own experiences. In addition to the need voiced by PLHAs and carers that grants and food for daily survival was required, the fact that having AIDS caused poverty which was reason for people to isolate themselves socially. Although the UNAIDS have not assigned poverty as an important factor for stigma, there is the increasing recognition of the downward spiral and vicious synergy AIDS has with poverty. In South Africa, like many

other countries where the poor are in the majority and have like in close proximity to the have-nots, poverty in itself is a stigma. The poor in South Africa are looked down upon, despised and discriminated against and tiny differences in degrees of poorness are used by the poor to discriminate against each other. Poverty should be recognized as a cause of stigma, it should be spoken about, and of course, eradication of poverty is core to the eradication of AIDS as well as many other diseases.

Modern day Soweto has a tradition of active Christian practice. As people seek to understand and find meanings to this epidemic the concept of pollution has sometimes been interpreted or mixed with western biomedical and Christian beliefs to form a powerful hybrid understanding which acts as another driving force for discrimination.

In South Africa many ethnographies have described the notion of 'pollution', (in isiZulu 'nyawa...') which is assigned to the meanings of illness, birth and death. Pollution, according to Ngubane is a "mystical or ethereal force", it creates conditions of misfortune and repulsiveness.

In its purest sense the 'mystical force' of pollution is concerned with the well-being of the whole society. Because it is closely connected with birth and death situations, it guarantees the continuity of society. Ngubane writes "in the interpretation of illness and its treatment, we see an elaborate and ordered system of ideas and practice. It is a coherent view that prevails even now in a society that has faced repeated and continued stresses. It has probably sustained the people and provided them with deep and satisfying answers to suffering brought by illness and misfortune'. There are a series of cleansing rituals and behaviours

which can counteract the misfortunes brought about by pollution. If these are not adhered to, further deaths can occur. (41)

Some informants have noted that the scale of the epidemic with associated costs (monetary and time) simply does not permit some of the rituals which prevent the effects of pollution. These practices can be seen to be rapidly changing in the face of the epidemic. Skhosana in her work in Soweto five years previously has noted that AIDS deaths were treated differently.

Belief of notions of pollution has led some in the health care sector to think that biomedical explanations of the modes of transmission are not understood. They believe that patients can only accept one belief system. On the contrary, informants in this study clearly understood that HIV is sexually transmitted, but that they are also worried about pollution. Many writers have described the existence of multiple views as a 'tension...which has been resolved in favour of...' or as one belief 'displacing' another.(42). However as discussed above Capra asserts that an individual may belong to several different cultures at one time. This existence of multiple values on a micro or individual level can be seen as a strength. By acknowledging and understanding all the influencing value systems, rather than singling out one single approach more coherent strategies can be formed to combat stigma and discrimination. (43)

There are many differing understandings of what culture is. The Columbia Encyclopedia defines it as 'the integrated system of socially acquired values, beliefs and rules of conduct that delimit the range of accepted behaviors in any given society'. Capra writes that culture arises from a complex highly non-linear dynamic. He asserts that it is created by a social network involving multiple feedback loops through which values, beliefs and rules are

continually communicated modified and sustained. He further elaborates that this system creates an identity amongst members sharing values and beliefs. People in different cultures have different identities because they share different sets of values and beliefs. He also states that an individual may belong to several different cultures at the same time. This may be seen in South Africa, where an individual from Soweto may express any or many of the following cultural identities; 'ethnic' culture (Zulu), a religious culture (Christian), and racial cultural identity (black, formerly oppressed), ex-rural now urban (was of peasant now working class) in a MTV culture, influenced by liberation, Sesotho wife, educated in western empiricism and African wisdom and so on. In different circumstances one or more identities may come to the fore.

This study found that multiple cultural identities mean that people do not see contradictions or tensions when seeking both traditional and western care. However, the data showed that cost has become an inhibiting factor to seeking traditional healers. This has been noted in another quantitative study. Contrary to a much quoted figure from one study, that 80% of black South Africans consult traditional healers (44) a study in the city of Johannesburg sampled over 1000 domestic workers. Only 15% had seen a traditional healer in the last year and 1/3 had seen a western doctor in the past three months. We need to further understand how changing practices and the inability for many to afford the rituals which counteract pollution affect attitudes and behaviour towards AIDS and people with AIDS.

The correct perception that health care services are curative is another barrier to uptake of palliative care. If palliative services are to be accepted and used then the community and the medical professions need to be re-educated. At present people with an incurable illness, are

told at some point that “there is nothing more the doctors can do”. Traditional healers use other criteria for assessing when they can no longer help a patient, and often give meaning to the terminal illness.

Needs of patients and their families and their expectations for palliative care services

Food

This study highlighted the need for food as an overriding concern. In Southern Africa food shortages, triggered by aberrant weather conditions and governance related failures have been made worse by the AIDS epidemic. (SACD, 2003). The effects of food insecurity on rural and agrarian communities have been clearly documented. South Africa has a 52% urban population, and the extent and type of food shortages in Soweto (qualitative and quantitative) needs urgent research. There is emerging work to show an increase in malnourished children in Soweto. However this study has also found a concern of not being able to afford the “right type of food”.

Despite the fact that currently there is no convincing scientific evidence that eating the ‘right food’ can significantly prolong the time before the development of AIDS, it is a common belief that people get ill and die because they did not or could not eat “properly”. There is also a lack of clarity as to what the ‘right food’ is, whether a healthy (African) diet which everyone should be eating is adequate for those with HIV. To what degree does access to calories, the right combination of carbohydrates, fats and protein prevent wasting and other illnesses are not clear. Despite a commonly held belief studies have not shown that the onset of AIDS can be prevented with diet alone.

The preoccupation with food may reflect the influence of the Health Minister who in numerous speeches has placed much emphasis on “healthy eating” for people infected with AIDS. It may in part be because it is a domain in life where people can take responsibility in looking after themselves and does not require a professional or a prescription.

Medication and the Disease trajectory of AIDS

Pain and serious symptoms are common in HIV/AIDS. More than 80% of people with AIDS have more than three pains and often suffer with multiple symptoms(45). Indeed HIV infected non-immune compromised or those on ARV medication also suffer a variety of pains and symptoms which can severely affect the quality of life.

Pain and symptoms, though, may not always be readily expressed. Common cultures in Soweto do not encourage complaining, crying or other expressions of pain.(46) Women in this study generally were not forthcoming about their suffering, unless asked specifically. Women especially are expected to go about their lives without complaining of pain.

Nevertheless, it was clear that access to medication was an important need. A survey of palliative care services in Sub-Saharan Africa showed that 94% of services could not provide adequate pain relief to their clients(47).

This contrasts with trends in developed countries, where, incidentally, pain and symptom relief are widely available. Institutionalization and medicalisation of care for the dying has been criticized for their dehumanizing aspects. The call for ‘demedicalisation’ of care of the terminally ill has seeped into policies and practice in developing countries. Most notable home based care programmes. However, studies in developing countries show that consumers are demanding more ‘medicalisation’ or more access to drugs and professional care. This should be noted when shaping policy in developing countries.

Approaching living with HIV and dying from AIDS through a cultural or a sociological lens

Death and the sun are not to be looked at steadily. La Rochefoucauld. 1613-80 maxims

As recommended in palliative care texts, this study set out to find out what cultural considerations were needed for palliative care for Soweto. The data demonstrated an unwillingness of Sowetans to dwell on death or to confront their illnesses. This is explored from two perspectives. Firstly, whether not talking openly about death and AIDS reflect a 'denial' or 'lack of a biomedical understanding about a disease' or is it a rational psychological reaction to death on a large scale. Secondly, whether current palliative care models which advocate an approach that encourages 'facing up to the prognosis', "dealing or working through the problem" are appropriate or even harmful. Should we be taking a cultural or sociological theoretical perspective on this?

This study has found that dwelling on death not an appropriate response. However this does not mean that we have not found people being open about their daily reality. Popular press and perceptions of the public are that South Africans are in denial or that AIDS is so taboo that they will not acknowledge its existence. Recent studies have shown the contrary and have explained this as a misinterpretation of the use of language. Metaphors, coded talk are commonly used. Skhosana points out that whilst critics were dismayed that at the funeral

of Parks Mankahlana no one mentioned AIDS directly in the “cause of death” oration, it was glaringly obvious to local people by the language used. This has been reiterated by Wood and Dowling in their work. Small argues that this is systematic in the way the “[West] attempts to seek to restructure the world in its own image, either through aggressive promotion of a particular approach or through the misinterpretation of the cultural codes and meanings of non-westerners.”

Western models of palliative care are based on some of the following principals of communication in order to provide excellent pain and symptom relief:(48)

- Open and honest discussion of the disease and prognosis with the patient (and family if appropriate) so the patient can come to terms with and accept their diagnosis and accept their impending death. In order to do this it requires some dwelling on the meaning of the disease and death.
- Helping the patient to come to terms with any spiritual pain also implies some thinking about death.
- Not encouraging collusion. (i.e. when the family and health care providers know the diagnosis and work together to hide it from the patient.)
- Acknowledging and working with anticipatory grief with the family.
- Being culturally sensitive when communicating about death. There is an attempt when western models of medicine are placed in non-western contexts (even when providing care to immigrants in the UK) to culturally adapt them, or to make them “culturally sensitive”. The use of fact files is one such example. This simplistic approach necessitates a static view of culture and pigeonholes people into

convenient cultural categories, and ignores the roles of the politico and socio context.

These principals were not developed for the situation of masses of deaths of young people but to cater for the needs of fewer deaths of mainly elderly people.

And are challenging to apply when one needs to use coded talk, and metaphors, and when dwelling on death is not wanted.

Not wanting to dwell on death is not a culturally specific reaction or denial but a universal human reaction when suffering and death happens on a large and uncontemplatable level.

Nadezhda Mandelstam, wrote of the Nazi concentration camps;

“our way of life kept us firmly rooted to the ground, and was not conducive to the search for transcendental truths...in war, in the camps and during periods of terror, people think much less about death, (let alone suicide), than when they are living normal lives.” Tr Max Hayward 1970.

Sowetans in this study echoed this sentiment.

“there is nothing I think about death’

“I don’t think about death. I just tell myself that God is there when my time comes”

The belief that that ‘thinking too much’ weakens the immune system and so makes you die faster. This is a common belief, prevalent in times of hardship even prior to the AIDS epidemic.

The author has had personal experience of deaths of South African political exiles in Tanzania, and Angola in the 1980’s; she often heard the following advice:

“Do not think too much, you will run mad”.

AIDS deaths and mourning

AIDS has been recognized for its uniqueness and otherness as a disease (ref). In the section above I have spoken about the fact that AIDS is unlike other terminal illnesses, because families experience multiple deaths, often across generations. The scale of the epidemic can be likened to a natural disaster or war. However, war, unlike AIDS has a meaning (people die for freedom or defending something). It is unlike a natural disaster which usually does not go on for decades.

AIDS in high HIV prevalence countries needs a palliative model that caters for living, dying and the deaths of huge numbers of young people. This requires re-examining the fundamental approaches to anticipatory grief, social death, bereavement, open discussion and collusion. The implications of this may be pertinent to HIV prevention interventions understanding risk taking behaviour of youth.

Post traumatic stress disorder (PTSD) has been identified as one common reaction to death in wars or natural disasters. Understanding PTSD in the South African context may inform more useful interventions.

Other strategies used to cope with mass deaths, on a scale is too large to make any sense of is by national (or international) memorialisation. There are numerous examples of this throughout history. Most of these memorialisation occurred after the event as a nations attempted to heal or to come to terms with the disaster. South Africa had a Truth and Reconciliation Commission after the end of the Apartheid era. As mentioned above South Africa is at the start of an epidemic that threatens to go on for many more years. Whether

memorialisation is appropriate in the midst of this epidemic, and what shape it should take needs discussion.

Grieving at a household and community level is often not possible due to lack of money, competing priorities, fractured or dissolved households, no time to grieve each individual. Mental health impact of this has not been assessed. Whether the suffering and loss requires both individual mental health care and healing of the national psyche needs to be addressed.

Changing cultures

South Africa has witnessed profound and rapid changes in society in the past 100 years. In Soweto mourning rituals have changed rapidly out of necessity.

How the changes in the unique 'epidemiology' of death in South Africa have affected culture and how culture has shaped needs of the dying needs to be addressed if we are to provide services that are useful and relevant to the user.

Skhosana has noted the changing culture in Soweto in five years, a popular practice of fancy funerals, where people wear fashionable and expensive clothes, and the 'after tears' parties has emerged. She contrasts this to the disciplined and martyred "political" funerals of the 1980's. What are the main forces driving this change in culture and why does culture change? Theodore Dobzhansky writes that culture is an instrument of adaptation. It is vastly more efficient than the biological processes which lead to its inception and advancement. It is more efficient amongst other things because it is more rapid - changed genes are transmitted only to direct descendents of the individuals in whom they first appear...changed culture may be transmitted to anybody regardless of biological parentage, or borrowed ready-made from other peoples. It may also be imposed on other peoples.

The culture of death as witnessed by funeral practices and beliefs around death in all societies protect the living from the effects of loss of a member of their community, and helps to heal those who had to witness the demise, and helps people face the fear of their own mortality.

Despite that fact that deaths of individuals are accorded different values, deaths of 'less societal significance' (newborns, the impoverished, women) are often no less painful to their loved ones. Mass deaths in a disaster of unfathomable proportions, do not become less painful. Being 'death-experienced' does not blunt the pain of grief. Understanding what aspects of current beliefs and attitudes are effective coping mechanisms, what aspects are barriers, if there is breaking point and which are effective interventions require urgent interdisciplinary studies.

Limitations of the study

This was an extraordinarily difficult subject matter to address for the following reasons; Discussing pain, suffering and deaths was difficult for both the fieldworkers and the informants. The common belief that talking about a topic brings it to you has been described often. The stigma of AIDS, poverty, fatal illness and death all were present here. Witnessing the pain and suffering was traumatic for the fieldworkers, despite psychological counseling they went about their work diligently but with a heavy heart and increasing sadness. Compounded by the fact that the epidemic has affected all, including the researchers. Since the subject matter was sensitive interviews were difficult to conduct and sometimes had to be abandoned so as not to tire or distress weak and sick patients or grieving carers.

Obtaining audible taped interviews was a challenge either because of background noise or perhaps they were too weak and talked quietly. Of the 57 interviews all but two yielded audible data for most of the interview, field workers notes were used to supplement the tapes.

Trust between the fieldworkers and informants had to be built up in a short space of time due to budgetary constraints.

Although South Africa has over 50% of its population living in urban environments, many would argue that Soweto is unique. The generalisability of these results may be limited although because many Sowetans have homes in the rural areas and the interactions and exchange of ideas and beliefs are abundant. Being the largest township in South Africa this study has important implications for service delivery.

The call for a multidisciplinary approach and the recognition of the complexity and dynamism of the lived experiences of death and dying is certainly important in the South African context of a burgeoning AIDS epidemic. The difficulty in doing this was evident when a medical doctor and anthropologist had to become familiar with each other's disciplines.

CONCLUSION AND RECOMMENDATIONS

- The widespread and somewhat convenient belief amongst many health planners in government and donor bodies about the existence of extended caring families in a tight-knit community with inexhaustible amounts of emotional and material support were often not evident. This belief has been supported by older work and is still prevalent despite later work by the WHO the spirit of 'ubuntu' inevitably wears thin as poverty deepened. Although we witnessed much kindness and caring in even the most materially deprived homes, it was common to find families, broken and ground down by poverty, simply trying to survive and who could not always be accommodating by absorbing yet another child, another niece/son/neighbor. Households and communities are not coping.
- South Africa has a unique epidemiology of death, that has shaped reactions to death on a large scale. This is mainly characterized by not wanting to dwell on death and dying and not wanting to talk about it.
- Stoicism is a barrier to expression of pain and symptoms
- Stigma is associated with poverty and the inability to cure AIDS. Good treatment services such as ARV access and excellent palliative care should reduce stigma.
- Rituals, cultural practices are rapidly changing in Soweto
- Sowetans hold multiple belief and values systems and will access different care systems simultaneously.

Recommendations

- Pain and suffering is not always readily expressed, should be taken into account when doing research on pain and symptoms and when providing good palliative care in Soweto.
- The debate that palliative care /care for those with AIDS should take cognizance of the scale of the epidemic.
- Interventions to mitigate grief and bereavement should not be western models which are culturally adapted but should take cognizance of sociological and historical factors
- Fatigue caused by AIDS should be acknowledged as a important and debilitating symptom.
- The findings have been used to initiate discussions with policy makers in the Gauteng Department of health.

REFERENCES

Reference

- (1) Harding R HIJ. **Palliative care in sub-Saharan Africa: an appraisal** . London: Diana, Princess of Wales Memorial Fund.; 2005.
- (2) Harding R, Easterbrook P, Dinat N, Higginson IJ. Pain and symptom control in HIV disease: under-researched and poorly managed. *Clin Infect Dis* 2005 Feb 1;40(3):491-2.
- (3) National Guideline on Homebased care/ community based care, Department of Health South Africa, (2005).
- (4) Harding R, Easterbrook P, Dinat N, Higginson IJ. Pain and symptom control in HIV disease: under-researched and poorly managed. *Clin Infect Dis* 2005 Feb 1;40(3):491-2.
- (5) Bradshaw D, Groenewald P, Laubscher R, Nannan N, Nojilana B, Norman R, et al. Initial burden of disease estimates for South Africa, 2000. *S Afr Med J* 2003 Sep;93(9):682-8.
- (6) Bradshaw D, Groenewald P, Laubscher R, Nannan N, Nojilana B, Norman R, et al. Initial burden of disease estimates for South Africa, 2000. *S Afr Med J* 2003 Sep;93(9):682-8.
- (7) Groenewald P, Nannan N, Bourne D, Laubscher R, Bradshaw D. Identifying deaths from AIDS in South Africa. *AIDS* 2005 Jan 28;19(2):193-201.
- (8) Bradshaw D, Groenewald P, Laubscher R, Nannan N, Nojilana B, Norman R, et al. Initial burden of disease estimates for South Africa, 2000. *S Afr Med J* 2003 Sep;93(9):682-8.
- (9) Grahamstown Hospice. Grahamstown Hospice "Quality of Life" Project. 2005.
- (10) Kalish RaDKR. *Death and Ethnicity: A Psychocultural Study*. New York: Baywood Publishing Company, Inc.; 2005.
- (11) Murray SA, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers. *BMJ* 2003 Feb 15;326(7385):368.
- (12) Kikule E. A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. *BMJ* 2003 Jul 26;327(7408):192-4.

- (13) Goudge J GLML. How to 'roll-out' CBO provided home-based care for AIDS: Government's role? UNiversity of the Witwatersrand: Centre for Health Policy Studies; 2005.
- (14) Murray SA, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers. *BMJ* 2003 Feb 15;326(7385):368.
- (15) Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med* 2003 Jul;57(1):13-24.
- (16) UNAIDS. 2004 Report on the Global AIDS Epidemic; 4th Global report. 2004.
- (17) Death, Gender and Ethnicity. Routledge; 2005.
- (18) Tessa Marcus. Living and Dying with AIDS. second. 2005. CINDI Network. Ref Type: Serial (Book, Monograph)
- (19) Middleton W, Moylan A, Raphael B, Burnett P, Martinek N. An international perspective on bereavement related concepts. *Aust N Z J Psychiatry* 1993 Sep;27(3):457-63.
- (20) Oxford Textbook of Palliative Medicine. 3rd ed. Oxford: Oxford University Press; 2003.
- (21) Death, Gender and Ethnicity. Routledge; 2005.
- (22) Yasmin Gunaratnam. Culture is not enough: a critique of multi-culturalism in palliative care. In: David Field JHNS, editor. *Death, Gender and Ethnicity*. Routledge; 2005. p. 166-87.
- (23) Rev Carlos Sandoval. Culture and Care. In: J F O'Neill PASHS, editor. *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS*. Department of Health and Human Services. USA; 2005. p. 301-14.
- (24) Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med* 2003 Jul;57(1):13-24.
- (25) Fassin D, Schneider H. The politics of AIDS in South Africa: beyond the controversies. *BMJ* 2003 Mar 1;326(7387):495-7.
- (26) Skhosana N. Women, HIV/AIDS and Stigma - an anthropological study of life in a hospice University of the Witwatersrand; 2005.
- (27) Connolly C, Shisana O, Colvin M, Stoker D. Epidemiology of HIV in South Africa--results of a national, community-based survey. *S Afr Med J* 2004 Sep;94(9):776-81.

- (28) Bradshaw D, Schneider M, Dorrington R, Bourne DE, Laubscher R. South African cause-of-death profile in transition--1996 and future trends. *S Afr Med J* 2002 Aug;92(8):618-23.
- (29) Bradshaw D, Groenewald P, Laubscher R, Nannan N, Nojilana B, Norman R, et al. Initial burden of disease estimates for South Africa, 2000. *S Afr Med J* 2003 Sep;93(9):682-8.
- (30) Wood K. An ethnography of sexual health & violence among township youth in South Africa London School of Hygiene and Tropical Medicine; 2005.
- (31) Health Systems Trust. South African Health Review 2001. 2005.
- (32) Seale C. Changing patterns of death and dying. *Soc Sci Med* 2000 Sep;51(6):917-30.
- (33) Seale C. Changing patterns of death and dying. *Soc Sci Med* 2000 Sep;51(6):917-30.
- (34) Harding R HIJ. Palliative care in sub-Saharan Africa: an appraisal . London: Diana, Princess of Wales Memorial Fund.; 2005.
- (35) Norval DA. Symptoms and sites of pain experienced by AIDS patients. *S Afr Med J* 2004 Jun;94(6):450-4.
- (36) Fantoni M, Ricci F, Del BC, Izzi I, Damiano F, Moscati AM, et al. Multicentre study on the prevalence of symptoms and symptomatic treatment in HIV infection. Central Italy PRESINT Group. *J Palliat Care* 1997;13(2):9-13.
- (37) Ngubane H. *Body and mind in Zulu Medicine: an ethnography of health and disease in Ntswa-Aula thought and practice*. London: Academic Press; 2005.
- (38) Kikule E. A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. *BMJ* 2003 Jul 26;327(7408):192-4.
- (39) Murray SA, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers. *BMJ* 2003 Feb 15;326(7385):368.
- (40) Naidoo V. Soweto Household Survey. 2005.
Ref Type: Unpublished Work
- (41) Ngubane H. *Body and mind in Zulu Medicine: an ethnography of health and disease in Ntswa-Aula thought and practice*. London: Academic Press; 2005.
- (42) Seale C. Changing patterns of death and dying. *Soc Sci Med* 2000 Sep;51(6):917-30.
- (43) Capra F. The Hidden Connections. Flamingo; 2002.

- (44) Peberdy S DN. Domestic workers, Migrancy and HIV. 2005.
Ref Type: Unpublished Work
- (45) Larue F, Fontaine A, Colleau SM. Underestimation and undertreatment of pain in HIV disease: multicentre study. *BMJ* 1997 Jan 4;314(7073):23-8.
- (46) Ngubane H. *Body and mind in Zulu Medicine: an ethnography of health and disease in Nyuswa-Aula thought and practice*. London: Academic Press; 2005.
- (47) Harding R HIJ. *Palliative care in sub-Saharan Africa: an appraisal* . London: Diana, Princess of Wales Memorial Fund.; 2005.
- (48) Robert Twycross. *Introducing Palliative Care*. first economy reprint ed. Calicut: Harvest Media Services; 2005.